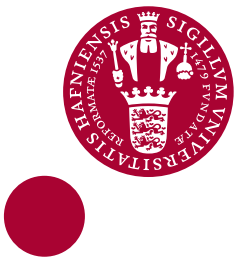

# Tracking failing biologies

## Book review : Local Cells, Global Science - A. Bharadwaj and P. Glasner & The Woman Who Walked into the Sea - A. Wexler

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**Tracking failing biologies**

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*Local Cells, Global Science: the Rise of Embryonic Stem Cell Research in India*, by Aditya Bharadwaj and Peter Glasner, Routledge, 2009, pp. 152, £80.00
*The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*, by Alice Wexler, Yale University Press, 2008, pp. 288, $30.00

The contrast between the two settings of Alice Wexler's *The Woman Who Walked into the Sea* and Aditya Bharadwaj's (with Peter Glasner) *Local Cells, Global Science* could not be starker: nineteenth century East Hampton on the easternmost tip of Long Island in rural America with its fields of grain, horse wagons, beaches and village church bells, and twenty first century 'neo-India' (New Delhi and Mumbai) where bullock carts and BMWs jostle for space in a cacophony of crowded urban streets. The tasks at hand are also methodologically distinct as Wexler historically traces the making of a hereditary (later genetic) disease and Bharadwaj ethnographically tracks the rise of embryonic stem cell research in India. Yet the two books read very well together, not least because of their focus on what might be described as the social experience of human biology: as a locus for bio-social identities and groupings; as a ground for exclusion/marginalisation; as a (bio-)valuable, exchangeable and exploitable resource; or as a form of expert knowledge. That is to say, the different ways in which contested biological science can inform and impact upon lived experience and vice versa.

Wexler's book opens with a striking clipping taken from the June 30th, 1806 edition of East Hampton's *Suffolk Gazette*. The report, which is placed just above a wanted ad for "a negro girl from eighteen to thirty years of age", recounts the circumstances surrounding the death of Phebe Hedges, wife of distinguished town trustee Captain David Hedges: "[T]here is every reason to believe she has precipitated herself into the surf which washes the south shore… This extraordinary step is attributed to her extreme dread of the disorder called St. Vitus' dance, with which she began to be affected, and which her mother has to a great degree" (p.3). This vignette provides the perfect entry point for a historical investigation into the social experience of families suffering from what is today known as Huntington's disease and which through the past two centuries has gone by the names of St. Vitus' dance, the magrums, hereditary chorea and Huntington's chorea.

*The Woman Who Walked into the Sea*, Wexler explains, is a continuation of her autobiographical account of living in a family with Huntington's disease (*Mapping Fate* from 1995). "I was well acquainted with the stigma and silences surrounding [Huntington's disease] in the late twentieth century. But I wanted to know whether it had always been this way, or whether in the past this illness – and those affected by it – may have been viewed differently" (p. xix). Using Phebe Hedges' family and descendants as

an example of how St. Vitus' dance could generate dread but not necessarily lead to family exclusion in 19th century East Hampton, Wexler argues that processes of stigmatisation and exclusion were particularly intensified in the late 19th and early 20th centuries as degeneration theory flourished and eugenicists accused hereditary diseases of weakening population 'quality' or 'stock'. Indeed, Huntington's was considered doubly degenerative – degeneration as a disease process in the brains of those who have inherited it and as biologically-rooted social and moral deterioration (p.103) – and perhaps therefore a particularly potent target for eugenic elimination through sterilisation.

Fast-forward to the 21st century and biological science, it is claimed, is once again on the brink of a new revolutionary solution to the problem of degeneration: regenerative medicine. This time, fertilisation rather than sterilisation is the key. Bharadwaj's *Local Cells, Global Science* tells the story of embryonic stem cell research in India as a journey of dis-location, bio-crossing, sacrifice and miracle, haunted by the menacing figure of the maverick/quack scientist. With countries like India, China and South Korea self-identifying as 'emerging biotech powers' (see Gottweis 2009), biological science has been dis-located as have North-South and First World-Third World dichotomies. Embryonic stem cell science in India, Bharadwaj shows, requires individuals who are bio-available in a dual sense. In Vitro Fertilisation (IVF) patients become available through consent processes to stem cell science through the extraction of egg and sperm cells (some of which are destined to become 'spare embryos' once combined) while patients with incurable diseases make themselves available through consent processes to experimental stem cell therapies. In turn, cultivated embryonic stem cell colonies generated from 'spare embryos' become bio-available to stem cell therapy patients once inserted into their 'failing biologies' (with the hope that degenerated, damaged or depleted tissue will be regenerated) (p.45).

Bharadwaj argues that this flood of bio-crossings – as biogenetic entities are transferred 'across the borders of biology, between biology and machine, and across geo-political, commercial, ethical and moral borders' (pp. 43-44) – is taking place in a multitude of 'liminal third spaces' that have emerged in and around neo-India. We are shown how India is simultaneously admonished and admired for its 'lax' regulation of stem cell science as it continues to build up a bioethical regulatory infrastructure modelled on European and American frameworks. We are also shown how Dr. Gheeta Shroff is simultaneously portrayed as miracle worker and maverick scientist as she offers injections of embryonic stem cells to paralysed patients or sufferers of Parkinson's disease. And finally, we are shown how the 'consenting' of infertility patients to gain research access to their 'spare embryos' takes place in ambiguous contexts of 'desperation', gratitude and sacrifice.

One way to productively read Wexler's and Bharadwaj's books together is to help us think about how social responses to 'failing biologies' are historically contingent and always grounded in certain epistemic and socio-cultural contexts. To begin with, human biology is seen to fail individuals when, for example, impeding reproductive desires, diminishing quality of life or shortening lifespan. The theme of desperation runs through both Wexler's and Bharadawaj's accounts, from the 'extreme dread' of St. Vitus' dance

that apparently led Phebe Hedges to take her own life in 1806 to the 'desperate' IVF patients (who are unable to reproduce without laboratory assistance) and 'desperate' stem cell tourists (whose vital tissues have been damaged 'beyond hope' by disease or traumatic injury) whose biographies converge in Indian fertility/stem cell therapy clinics. In this sense, biological failure is an 'essential molecular mistake in the [Huntington's] gene' (Wexler p. ix), a tubular blockage preventing pregnancy or a wheelchair-confining broken spine, and following Canguilhem (1994), we might think of failure here as a kind of detraction from individual vitality – whether understood in terms of longevity, resilience, vigour or quality of life.

What is more, these individuals' suffering, Wexler and Bharadwaj show, is more often than not exacerbated by processes and fears of stigmatisation and marginalisation that surround disease and disability; for example, leading families in East Hampton to hide family members severely affected by Huntington's behind blankets or in attics or infertile patients in India to amass massive personal debts in the pursuit of fertility treatment without confiding in even the closest of family members or friends. That is to say, social experience of failing biologies can further detract significantly from an individual's or couple's vitality.

In the context of late 19$^{th}$ and early 20$^{th}$ century America, Wexler maps out the consequences of a 'new epistemic or conceptual space of heredity' (p.64) for the social experience of Huntington's disease. It was within such an epistemic space that degeneration theory as well as the positive and negative eugenic practices that it informed would emerge. In this configuration, failing biology was construed at a collective level in terms of a weakening 'population quality' or 'stock'. As already noted, hereditary diseases which were seen to be transmitted by persons of 'bad stock', were a primary target of eugenic sterilisation practices. At stake was the collective vitality of the nation or national population which had to be protected from reproducing degenerates. In this context, Huntington's chorea was a disease that could be tracked by compiling family pedigrees as it migrated throughout America, borne by families marked by a 'constitutional taint'. Medical journals carried articles claiming that certain individuals had been the 'lamentable means of transporting a family disease from England to the colonial states, which inheritance has spread throughout the United States' (p.166). Correspondingly, eugenic approaches to eradicating Huntington's chorea through sterilisation were famously proposed by Elizabeth Muncey and Charles Davenport in 1916.

Finally, Bharadwaj describes a third sense in which biology can be seen to fail, namely as an institutionalised science. Stem cell research carried out in contexts of vulnerability (on the part of both infertile patients who supply 'spare embryos' and patients of incurable diseases who experimentally receive embryonic stem cell lines by injection) is subject to intense scrutiny, perhaps especially so in the wake of South Korea's Hwang scandal (Jackson 2006). As a research activity requiring consenting human subjects, biology fails when deemed unethical. Consequently, the delineation of sound scientists from maverick or quack scientists in media reports, among scientists and by regulators has become a regular feature of the global stem cell science field. Bharadwaj argues that ethical

guidelines and regulations – which form part of a global moral economy of stem cell lines – imported to India from the United Kingdom and America have been flexibly implemented in a non-binding way. This flexibility forms a part of the liminal third space in which stem cell scientists have 'unrestricted access to "spare embryos" from [India's] many IVF clinics' (p.110), but also in which the figure of the maverick scientist emerges as globally problematic.

It is no coincidence that both Wexler and Bharadwaj invoke Paul Rabinow's notion of bio-sociality – i.e. 'how the emerging "truths" that are being produced about humans in the diverse field of genetics shape our identities and forms of group activism' (Gibbon and Novas 2008: 2) – in their analyses, for it is exactly around failing biologies that bio-social groupings have formed in recent decades. Families and individuals have, for example, formed new relationships 'centred around a shared identification with Huntington's' (Wexler, p.183), initiating such groups as the Huntington's Disease Society of America which funds biological research as well provides support for patients. Such bio-social groupings have been central in helping families with Huntington's transcend the stigmatisation documented in Wexler's historical study. Yet Bharadwaj's analysis and case provides an important note of caution against an assumption that failing biologies will automatically generate biosocial groupings irrespective of circumstances. Stem cell tourists travelling to India from America or Europe may well be part of emerging bio-social groupings (indeed stem cell therapy has been identified as promising by Huntington's disease advocacy groups), but for the majority of Indians who struggle to make ends meet 'constraints are multiple, from the unavailability of opportunity, and of resources, the inability to organize around a medical condition, syndrome or mutation, to social isolation, stigma and de-legitimation' (p.42).

What we learn then is that biology can only fail in a social context; biology cannot fail in and of itself. Through Bharadwaj's and Wexler's studies we are shown how biology has been seen to 'fail' when weakening 'population quality', diminishing quality of life, impeding reproductive desires or exploiting vulnerable individuals. In each of these cases, failing is socially mediated. Degeneration of population quality was considered a problem because of the social and moral degeneration attributed to it; inheritance of 'molecular mistakes' is a problem because of the impact these mistakes will have on an individual's (quality of) life; involuntary impediment of reproduction is a problem because of the social stigmatisation that childlessness can bear upon a couple; exploitative scientific research represents a failure of stewardship; etc. We are also shown how the formation of biological knowledge is an inherently social activity involving not only expert scientists, but also families, 'desperate' IVF patients or local communities.

With *The Woman Who Walked into the Sea*, Alice Wexler has helped to reconstruct historically the social, clinical and epistemic spaces in which St. Vitus' dance could transform into the genetic disease that it is today. She has convincingly demonstrated how it was St. Vitus's anchoring in a local community in East Hampton that enabled a young George Huntington to identify its dominant pattern of inheritance through observations and intimate knowledge of the community's families in the 1870s. Yet, ironically, it was exactly this new knowledge of Huntington's chorea as a hereditary

disease that eventually led to community ostracisation and stigmatisation for 'tainted' families in the early 20th century. In *Local Cells, Global Science*, Aditya Bharadwaj provides a sobering analysis of how headline-prone global stem cell science in *neo*-India cannot be separated from the local IVF clinics, infertile couples, 'spare embryos' and regulatory flexibility around which it is developing. By showing us how it is bio-availability rather than bio-sociality that 'desperate' infertile couples and seekers of stem cell therapy in India have in common, Bharadwaj reminds us that constraint and stigmatisation continue to shape the social experience of failing biologies.

When the books do fall short, this has much to do with methodological shortcomings. As forms of research, history and ethnography both require detective-like skills to track down sources and/or informants. Wexler is quite often left to speculate when sources have not been sufficient – e.g. 'here is what George Huntington *could* have known, from his own, his father's and his grandfather's observations' (p. 85), 'Surprisingly, the perception that the condition was inherited seems to have muted its stigmatization [in East Hampton]' (p.49) – raising questions about the blurring of historical reconstruction-construction. Bharadwaj's multi-sited ethnography shifts empirical focus just when the reader's interest has been caught and we are left with the feeling that each chapter is deserving of a monograph in itself (at pp.122 it is much too brief!). We want to learn much more about how Dr. Gheeta Shroff, her patients, infertile couples, regulators and others make up embryonic stem cell assemblages in India.

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